Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study

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Insights into the factors associated with achieving the preference of home death in terminal cancer: a national population-based study.

Authors

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Short Title:Factors associated with dying at home with cancer

List of Manuscript content:Number of Manuscript pages=12

Number of tables= 2

Number of supplementary tables= 1

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Abstract

Objectives: Most terminally-ill cancer patients prefer to die at home, yet only a minority achieve this.To investigate factors associated with cancer patients achieving their preference to die at home.

Methods: This study took the form of a mortality follow back, population-based, observational survey of relatives of deceased cancer patients in Northern Ireland. Individuals who registered the death of a friend or relative (aged≥18yrs) between 1/Dec/2011 and 31/May/2012, where the primary cause of death was cancer (ICD10: C00-D48) were invited to take part. Preferred and actual place of death,and patient, service and clinical data were collected using the Qualycare postal questionnaire. Multivariable logistic regression was used to investigate factors associated with achieving home death when this was preferred.

Results: 467 informants out of 1,493 invited completed the survey, 362 (77.5%) expressed a preference of dying at home *and* spent time at home in their final three months were included in analysis. Of these, 53.4% achieved their preference for a home death. Factors positively associated with achieving home death were living in an affluent area, receipt of the good satisfactory district nurse care, discussing place of death with health professionals, and carer's preference for a home death. Being aged >80, Presbyterian religion, and being unconscious most of the time in their final week, were negatively associated with a home death.

Significance of Results: Communication, care satisfaction and carer preferences were all associated with home death. The findings will help inform the design of future interventions aimed at increasing the proportion of patients achieving preferred place of death at home, for example, by targeting interventions towards older patients and those from the most deprived communities.

Keywords

Bereavement, Communication, Home care services, Cancer, Palliative care

Introduction

The End of Life (EOL) Care Strategy published by the Department of Health, London, (2008)highlights that one feature of good EOL care is enabling patients to die in their place of preference. For the majority of cancer patients,' this preferred place of death is home (Higginson & Sen-Gupta, 2000; Becarro et al., 2006; Brazil et al., 2005; Gomes et al. 2013). However, in Northern Ireland (NI), only 34% of cancer patients achieve this (Blaney& Gavin, 2011), in England 24.5% (Gao et al., 2013), in contrast to 45.4% in the Netherlands (Cohen et al., 2010). A systematic review identified patient factors such as longer disease duration, solid tumour diagnosis, low functional status,expression of preference for a home death by patient or carer, rural status, married, living with relatives, and family support, white ethnic status, good social conditions as all positively associated with dying at home (Gomes et al., 2006). Compared to those who die in hospital there is evidence of better psychological and social wellbeing among cancer patients who died at home (Higginson, et al.,2013) while a recent study also reported better outcomes for grief and peace for those who died at home (Gomes et al., 2015).

The likelihood of achieving one's preference to die at home is complex and far from being understood as few studies investigate many factors at the same time. The aim here was to apply a multivariate approach that can estimate the relative strengths of association of several factors on achieving a home death and identify possible causal factors that could form the basis for potential interventions to increase terminally-ill cancer patients' likelihood of achieving a preferred home death.

Methods

Survey

A population-based survey of bereaved carers of adult cancer patients (aged 18 and over), who died between December 2011 and May 2012, was carried out in NI using death registration data. The Demography & Methodology Branch of the Northern Ireland Statistics & Research Agency administered the survey confidentially on behalf of the study team. Those individuals who had registered the death of a person who died of cancer (defined by ICD10 codes C00-D48) in the previous 4-6 months were invited to participate in the survey. The questionnaire, which focused on the patient's final three months of life, considered the type and quality of care the patients received

(including care provided by informal carers, other family and friends), patient's health-related quality of life, palliative outcomes in the last week, the carer's perspective on care received and bereavement. The survey methodology was based on the Qualycare survey undertaken in London in 2009-10 (Gomes et al., 2010; Gomes et al. 2015), and the following tools, with adaptations, were included: Client Service Receipt Inventory (CSRI) (McCrone, 2009), Palliative Outcome Scale (POS) (Hearn &Higginson, 1999),EuroQoL EQ-5D (Xia et al., 2005).

Research question and study population

The study explored potential independent variables associated with a patient who was receiving care at home achieving their preference to die at home. The patient inclusion criteria were 1) expressed a preference to die at home, 2) had spent some time at home in their last three months of life. The binary outcome variable was 'died at home' (0/1). The potential independent variables were either drawn directly, or derived from one or more variables, from the questionnaire; as the study tested clearly-defined measures, only components of the scoring tools were used. The variables were classified into the following domains:

1. patient's demographics (sex, age, marital status, deprivation, religion),
2. patient's mental well-being,
3. patient's physical well-being,
4. patient's symptom severity,
5. how well the patient was informed about their treatment and place of death,
6. [perceived] quality of non-medical care provided at home,
7. quality of medical care provided at home,
8. quality of medical care provided outside the home,
9. carer factors (e.g. their relationship to the patient, their preferred place of death).

The independent variables' responses were simplified into binary variables (yes or no). All independent variables examined are listed in Supplementary Table I. A 'not-applicable' category was applied where appropriate.

Statistical analysis

The outcome variable 'died at home' was related to the independent variables using logistic regression. To address non-response bias, each record in the analysis was weighted by its inverse probability of participation in the study after invitation; this probability was estimated by relating, through logistic regression, the patient's participation (0/1) to their sex, age, socio-economic deprivation, and place of death.

The reference level of independent variables was set in such a way to output the odds-ratio association of interest, e.g. yes: no; a nuisance parameter was used for the category 'not-applicable' or 'unknown' to remove these patients' influence from the association of interest. The model independent variables consisted of a base set of the demographic variables (domain 1, Supplementary Table I) to which was added, singly, the variables across domains 2-9 (Supplementary Table I). The retained variables (with a coefficient significant at<0.05) formed, together with the domain-1 variables, an updated base set which was subject to a further round of single addition of variables through domains 2-9. The final list of variables for inclusion in the model is reported in Table II. Pairs of these variables were selected, considering effect sizes or a priori hypotheses, and tested for interaction along with the base set. Multivariate imputation (MI), using chained equations, was employed to handle missing values, when fitting the final model. Thevariables in the base set (Table II), which include the demographic variables, were used as the predictor equations for MI, and 10 sets of imputed data sets were combined to estimate effects and their standard errors. The analysis was carried out using Stata version 12.

Results

Of the 1,493 carers invited to participate in the study, 467 (31.3%) responded. The percentage of patients aged 60-69 was lower in the response-group than the non-response group (20.1% vs 41.0% P<0.001, Table I). Among the response-group, a greater proportion of patients was 1) from the 'mostdeprived'socio-economic quintile (17.3% vs 8.1%, P<0.05), and 2) died at home (38.1% vs 32.7%, P<0.05), than the non-response group. There was no difference in patient sex breakdown between response and non-response groups (P=0.80) (Table II).

Place of death preference of the 467 patients was distributed as follows: home 349 (74.7%), hospice 28, hospital 16, nursing home 8, elsewhere 1, no preference 23, carer did not know 42. Of those who preferred to die at home, 326 patients (69.8% of 467) spent some time at home and were included in the study. Of these, 53.4% achieved their preference for a home death. 99.0% of the patients' carers were relatives.

The final model, resulting from the forward-selection approach, is presented in Table II. The odds ratios derived from the multivariate analysis were sufficiently different from the univariate analysis to justify the former (particularly for deprivation). Factors that were positively associated with a patient's achieving their preference to die at home were living in an affluent area (least deprived: most deprived odds ratio [OR] 4.0 95% Confidence Interval [CI] 1.4–11.8), receiving the satisfactory care at home from a district nurse (yes: no OR 6.1 [95% CI 2.5–15.2]), discussing with a health-care professional their place of death (yes: no OR 4.7 [95% CI 1.9–11.5]), and the carer's preference for place of death (home: elsewhere OR 17.7 [95% CI 5.3–59.3]). Factors inversely associated with achieving one's desire to die at home were age (over 80 years: under 70 OR 0.5 (95% CI 0.2–1.0), being unconscious most of the time in the last week (yes: no OR 0.1 [95% CI 0.0–0.4]), and Presbyterian religion (Presbyterian: Catholic OR 0.30 [95% CI 0.11-0.87]).

In the final model, McFadden's coefficient of determination (R^2) (McFadden, 1974) for logistic regression was 46% and Tjur's (Tjur, 2009) R2 was 50%. The Hosmer-Lemeshow goodness of fit test had a P-value of ≥0.25 when the number of groups employed varied from 4—12. The likelihood-ratio test's P-value was >0.05 when testing for interactions in the model.

Discussion

This is one of very few national population-based studies exploring patient, service and clinical factors associated with achieving preferred place of death at home for terminally-ill cancer patients (Weitzen et al., 2003 and Cohen et al., 2010). Younger patients and those from more affluent areas had a greaterlikelihood of dying at home, as did those patients whose carer's preference was for a home-death. Discussion with a health professional about place of death, and good satisfaction with district nurse services increased the likelihood of achieving a home death.It is important to note that a greater

proportion of patients in the response group were from the ‘most deprived’ socio-economic quintile than the non-response group. This is in contrast to findings observed in a previous mortality follow-back study of a similar design (Gomes et al, 2015) which observed a quarter (25.3%) of respondents from the least deprived quintile and may have an impact the interpretation and representativeness of the findings.

It was encouraging that overall care was described as ‘good or excellent’ for the majority of patients across the different care settings (Supplementary Table I) suggesting a high standard of end of life care in a UK region. However, further qualitative work should be undertaken to investigate reported causes of dissatisfaction with care with a view to identifying improvements needed in palliative and end of life cancer care.

There was little evidence of an association between satisfaction with care and achieving a home death. However, those who felt they did not get the district nurse help they needed had significantly lower odds of achieving a home death. This perhaps reflected the extensive duties that district nurses perform spanning medical, hospice, and social support and is consistent with the conclusions from a review of factors associated with the congruence between preferred and actual death (Bell et al, 2010). While it is also possible that those dissatisfied with district nursing care had care needs that were more difficult to manage in a home setting, this was not apparent from the data collected in this study.

The importance of specific communication in achieving preferred place of death is evidenced with the strong, independent association between ‘discussion of place of death with a health professional’ and achieving a home death. As other direct patient-care factors were not so associated, it is likely that communication is more than a proxy for patient care. This may have been mediated both through patients and carers aligning preferences with care needs as well as a health care response to meet the preferences of patients and their carers (Bell et al. 2010). These findings reinforce the importance of clinician discussion about place of death reported in previous studies. This information should be recorded in the patient’s clinical record to allow routine audit and monitoring. This has previously been highlighted as a component of best practice in community palliative care in NICE Guidance on end of

life care(NICE, 2004) and has been reported in several research studies (Parker et al.,2007; Clayton et al., 2005). The extent to which this is applied is unclear.

In addition to communication, the role of family and carer support has been highlighted as very important in achieving preferred place of death. In particular, the carer's preference for place of patient's death three months prior to diagnosis was strongly associated with achievement of preferred place of death. This is consistent with a previous Japanese study (Ishikawa et al., 2013) that reported family preference for place of death is a mediator between patient preference and actual place of death and reflects the important role of carer support in end of life care in a home setting.

Family support may also explain the lower odds of Presbyterians achieving a home death compared to Church of Ireland, and Catholic denominations. Previous studies have reported smaller family size among Presbyterians compared to Catholics and other denominations (Compton et al., 1985). This is supported by the fact that Catholic respondents in this study were more likely to report family members looked after the patient (57%) than Presbyterian (38%) and Church of Ireland (30%) respondents ($p<0.01$). However, other cultural and social factors may also have a role in explaining this relationship. Future studies ought to include religion and ethnicity as demographic characteristics that may influence achievement of preferred place of death.

Despite the wide array of data collected on care and quality of life, the underlying drivers of the association between achieving a home death and demographic characteristics, such as younger age and living in more affluent areas, remain unclear. Though it is likely that these associations were mediated through social support, advocacy and communication, it is also possible that the pattern is explained by a greater burden of co-morbid disease in these populations, which may be manifested in more complex care needs of the patient, as well as limitations on carer capabilities.

Strengths and weaknesses

Few population-based studies have been undertaken to report end of life care experiences of cancer patients and little is understood about their care needs and satisfaction with care. The overall response rate was 31%, while a low response rate was expected, given the sensitive subject matter

and the target population surveyed, such response rates leave room for bias (Calanzani et al., 2016; Gomes et al. 2013). Comparing profiles of respondents to non-respondents, a greater proportion of non-responses were in the patient age-group 60-69, perhaps reflecting more spouse-carers who found participation difficult. In addition, responses were higher in patients living in lower socio-economic areas. Inverse weighting by response probability was applied to compensate for observed profile differences. In addition, multivariate analysis and multiple imputation of missing values were used to reduce bias in estimation of population effect sizes. The multivariable modelling approach succeeded in isolating a small number of variables with significant associations.

Another important issue for consideration was the fact that patient's preference of death was not canvassed directly, and therefore its measurement is open to misclassification. However, 19% of care-givers did not concur with the patient's preference for a home death which broadly agrees, if not higher, with other studies (Bell et al., 2010; Gomes et al., 2015), and suggests, at least, that carers were discriminating theirs and the patient's preference. Even so, as patient preferences are shaped by a complex of issues (Tang, 2003) each of which may change during their illness, future studies may consider a prospective assessment of patient's preference at variable time points.

Conclusions

Several factors have been identified as associated with achieving preferred place of death at home. Interventions must target groups at high risk of not achieving preferences including the oldest patients and those from more deprived communities. It is evident that the rapidly changing healthand care-requirements in the last weeks of life mean that these preferences may change and may not always be achieved, however, for many, undesirable hospital deaths can be avoided with clear communication about preferences involving patients, carers and healthcare workers. Achievement ofhome death has the potential to improve the psychological aspects of dying for patients and their families.

Acknowledgements

The authors thank Professor Irene Higginson and her research team at the Cicely Saunders Institute for the use of the instruments from the Qualycare study (funded by Cicely Saunders International). This study was funded by Cancer Focus NI and was carried out by the N. Ireland Cancer Registry which is funded by the Public Health Agency NI. We also thank the Northern Ireland Statistics and Research Agency for their facilitation of the survey methodology. Ethical approval was granted by Office of Research Ethics Committees Northern Ireland.

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Table I: Comparison between respondents and non-respondents' distribution of place of death anddemographic characteristics

Variable-categories	Non-respondents (n=1026)	Respondents (n=467)	All persons (n=1493)	P-value*
Place of death:				
NHS Hospital	449 (43.8%)	204 (43.7%)	653 (43.7%)	0.064
Home	335 (32.7%)	178 (38.1%)	513 (34.4%)	
Hospice	130 (12.7%)	43 (9.2%)	173 (11.6%)	
Nursing Home	112 (10.9%)	42 (9.0%)	154 (10.3%)	
Age groups:				
0-59	160 (15.6%)	62 (13.3%)	222 (14.9%)	<0.001
60-69	421 (41.0%)	94 (20.1%)	515 (34.5%)	
70-79	275 (26.8%)	154 (33.0%)	429 (28.7%)	
80+	170 (16.6%)	157 (33.6%)	327 (21.9%)	
Patient sex:				
Male	544 (53.0%)	251 (53.7%)	795 (53.2%)	0.80
Female	482 (47.0%)	216 (46.3%)	698 (46.8%)	
Socio-economic deprivation				
Most Deprived	83 (8.1%)	81 (17.3%)	164 (11.0%)	<0.001
2	144 (14.0%)	104 (22.3%)	248 (16.6%)	
3	373 (36.4%)	114 (24.4%)	487 (32.6%)	
4	265 (25.8%)	80 (17.1%)	345 (23.1%)	
Most affluent	161 (15.7%)	88 (18.8%)	249 (16.7%)	

*P-value: the probability that the distributions of respondents and non-respondents are the same (i.e. the null hypothesis) given the Chi-square statistic assuming independence, conventionally the null hypothesis is rejected in the P-value <0.05.

Table II: The association between a patient's desire to die at home and various explanatory factors explored through both univariate andmultivariable analysis								
Factors	Categories	Achieved preference to die at home [observed] (n=362)		Univariate analysis		Multivariate analysis[1]		
	Overall	N (42.0%=152/362)	Y (58.0%=174/362)	Odds ratio	P-value	Odds ratio	P-value	Predicted
Sex	Male (ref)	52.2% (96/184)	47.8% (88/184)	1	-	1	-	49.7% (42.8%,56.6%)
	Female	39.4% (56/142)	60.6% (86/142)	1.7 (1.1, 2.6)	0.023	1.6 (0.7, 3.4)	0.247	56.1% (48.7%, 63.4%)
Age Category	0-69 (ref)	42.5% (45/106)	57.5% (61/106)	1	-	1	-	53.2% (45.5%, 61.0%)
	70-79	42.6% (46/108)	57.4% (62/108)	1.0 (0.6,1.7)	0.984	1.8 (0.7, 4.2)	0.196	60.9% (53.1%, 68.8%)
	80+	54.5% (61/112)	45.5% (51/112)	0.6 (0.4, 1.1)	0.077	0.5 (0.2, 1.0)	0.049	41.9% (33.8%, 50.1%)
Religion	Catholic	37.8% (48/127)	62.2% (79/127)	2.2 (1.3, 3.8)	0.005	3.3 (1.2, 9.4)	0.026	58.3% (50.2%, 66.4%)
	Presbyterian (ref)	57.3% (51/89)	42.7% (38/89)	1	-	1	-	41.7% (31.6%, 51.8%)
	Church of Ireland	45.2% (28/62)	54.8% (34/62)	1.6 (0.8,3.1)	0.143	2.8 (0.9, 9.1)	0.088	56.1% (45.3%, 67.0%)
	Other	52.4% (22/42)	47.6% (20/42)	1.2 (0.6, 2.5)	0.597	2.0 (0.5, 7.4)	0.293	51.6% (36.6%, 66.6%)
	M	*3/6*	*3/6*	-	-	-	-	
Deprivation	Most Deprived	55.2% (32/58)	44.8% (26/58)	1	-	1	-	42.4% (31.9%, 52.8%)
	2	43.8% (32/73)	56.2% (41/73)	1.6 (0.8,3.2)	0.198	1.3 (0.5, 3.5)	0.624	46.0% (35.8%, 56.1%)
	3	39.5% (30/76)	60.5% (46/76)	1.9 (0.9,3.8)	0.072	2.6 (1.0, 7.3)	0.06	56.1% (47.0%, 65.3%)
	4	48.2% (27/56)	51.8% (29/56)	1.3 (0.6, 2.8)	0.458	2.1 (0.6, 6.6)	0.225	52.7% (40.9%, 64.6%)
	Most Affluent	49.2% (30/61)	50.8% (31/61)	1.3 (0.6, 2.6)	0.513	4.0 (1.4, 11.8)	0.011	61.8% (52.1%, 71.6%
	M	*1/2*	*1/2*	-	-	-	-	
Unconscious in the last week	Y	60.7% (17/28)	39.3% (11/28)	0.5 (0.2, 1.2)	0.108	0.1 (0.0, 0.4)	0.002	27.3% (6.3%, 48.3%)
	N (ref)	44.6% (129/289)	55.4% (160/289)	1	-	1	-	55.3% (50.5%, 60.2%)
	M	*6/9*	*3/9*	-	-	-	-	
Got the district nurse help needed at home	Y	32.2% (69/214)	67.8% (145/214)	7.0 (3.5,14.2)	<0.001	6.1 (2.5,15.2	<0.001	64.2% (58.3%, 70.0%)
	Otherwise (ref)	76.9% (40/52)	23.1% (12/52)	1	-	1	-	34.9% (21.5%, 48.4%)
	Not applicable[2]	75.5% (40/53)	24.5% (13/53)	1.1 (0.4, 2.7)	0.518	0.4 (0.1, 1.3)	0.123	20.2% (7.7%, 32.8%)
	M	3/7	4/7	-	-	-	-	
Place of death discussed with HCP	Y	27.2% (40/147)	72.8% (107/147)	4.8 (2.8, 8.3)	<0.001	4.7 (1.9, 11.5)	0.001	62.4% (55.2%, 69.6%)
	N (ref)	64.4% (67/104)	35.6% (37/104)	1	-	1	-	39.3% (29.9%, 48.6%)
	M	*45/75*	*30/75*	-	-	-	-	
Carer's preferred place of death	At home	37.2% (99/266)	62.8% (167/266)	12.1 (4.6, 32.0)	<0.001	17.7 (5.3, 59.3)	<0.001	59.2% (53.6%, 64.8%)
	Elsewhere (ref)	87.8% (36/41)	12.2% (5/41)	1	-	1	-	17.0% (4.6%, 29.4%)
	No preference[3]	88.9% (16/18)	11.1% (2/18)	0.9 (0.2, 5.1)	0.906	0.8 (0.1, 4.3)	0.798	14.7% (2.0%, 27.4%)
	M	*1*	*0*	-	-	-	-	

[1]T he multivariate analysis comprises all of the variables reported in this table. Multiple imputation was employed to deal with the missing (*M*) values. In addition each record was weighted by itsprobability of being sampled based on the variables in Table 1 for responders and non-responders.[2]Seven patients did not want help, and help was not needed for the remainder (n=40).

Supplementary Table I: List of variables taken directly, or derived, from the questionnaire and classified into domains, with each variable's categories and numbers in each of categories.

Variable domain	Question variable	Categories (y=yes, n=no, na=not-applicable, m=missing)
Patient's demographics (=1)	Patient is married or with partner?	y=198, n=123, m=5
	Patient's religion	Catholic=127, Presbyterian=89, Church of Ireland=62, Other=42, m=6
	Sex of patient	male=184, female=142
	Age at death of patient	0-69=106; 70-79=108; 80+=112 [mean 73.8]
	Patient's deprivation quintile	Most Deprived[1]=58, 2=73, 3=76, 4=56, Most affluent[5]=61, m=2
Patient's mental fitness (=2)	Extreme anxiety/depression at three months before he/she died?	y=25, n=292, m=9
	Extreme anxiety/depression in the last week?	y=68, n=231, m=27
	Confused in the last week before death most of the time?	y=42, n=278, m=6
	Over the last week, was patient feeling anxious or worried about illness or treatment most of the time?	y=48, n=272, m=6
	Over the last week, did patient seem to be feeling depressed most of the time?	y=46, n=265, m=15
Patient's physical fitness (=3)	Extreme anxiety/depression at three months before he/she died?	y=25, n=292, m=9
	Extreme anxiety/depression in the last week?	y=68, n=231, m=27
	Confused in the last week before death most of the time?	y=42, n=278, m=6
	Over the last week, was patient feeling anxious or worried about illness or treatment most of the time?	y=48, n=272, m=6
	Over the last week, did patient seem to be feeling depressed most of the time?	y=46, n=265, m=15
Patient's physical fitness (=3)	Did the patient stay in a hospital intensive care unit?	y=38, n=288
	Did the patient stay in another hospital unit or ward?	y=236, n=90
	Did the patient visit A&E?	y=169, n=156, m=1
	Did the patient use ambulance services?	y=176, n=149, m=1
	Confined to bed at three months before he/she died?	y=23, n=289, m=14
	Confined to bed in the last week?	y=262, n=53, m=11
	Unable to perform self care at three months before he/she died?	y=61, n=250, m=15
	Unable to perform self care in the last week?	y=279, n=40, m=7
	Unable to perform usual activities at three months before he/she died?	y=115, n=197, m=14
	Unable to perform usual activities in the last week?	y=309, n=12, m=5
Variable domain	**Question variable**	**Categories (y=yes, n=no, na=not-applicable, m=missing)**
Patient's symptom severity (=4)	Unconscious or in a coma during the last week before death most of the time?	y=28, n=289, m=9
	Over the last week, was the patient affected by pain despite medication most of the time?	y=90, n=229, m=7
	Over the last week, did other symptoms seem to affect how patient was feeling most of the time?	y=78, n=241, m=7

	Severe/overwhelming weakness or lack of energy in the last week despite medication	y=272, n=43, m=11
	Severe/overwhelming shortness of breath in the last week despite medication	y=142, n=176, m=8
	Severe/overwhelming nausea in the last week despite medication	y=64, n=246, m=16
	Severe/overwhelming vomiting in the last week despite medication	y=38, n=263, m=25
	Severe/overwhelming constipation in the last week despite medication	y=66, n=238, m=22
	Severe/overwhelming diarrhoea in the last week despite medication	y=38, n=260, m=28
	Severe/overwhelming drowsiness in the last week despite medication	y=152, n=160, m=14
	Severe/overwhelming difficulty communicating in the last week despite medication	y=102, n=208, m=16
	Extreme pain/discomfort at three months before he/she died	y=58, n=258, m=10
	Extreme pain/discomfort in the last week	y=164, n=144, m=18
How well the patient was informed (=5)	Did GP in the home listen and discuss things fully with the patient or carer?	y=239, n=83, na=2, m=2
	Did palliative specialists in the home listen and discuss things fully with the patient or carer?	y=187, n=25, na=110, m=4
	Did nurse in the home listen and discuss things fully with the patient or carer?	y=209, n=35, na=75, m=7
	Did hospital doctors listen and discuss things fully with the patient or carer?	y=163, n=87, na=74, m=2
	Did hospital nurses listen and discuss things fully with the patient or carer?	y=152, n=88, na=84, m=2
	Did hospice doctors listen and discuss things fully with the patient or carer?	y=36, n=9, na=281
	Did hospice nurses listen and discuss things fully with the patient or carer?	y=37, n=8, na=281
	In the care home, did nurses listen and discuss things fully with the patient or carer?	y=14, n=5, na=306, m=1
	In the care home, did the GPs listen and discuss things fully with the patient or carer?	y=19, n=4, na=302, m=1
	In the care home, did the palliative specialist listen and discuss things fully with the patient or carer?	y=3, n=2, na=321
	In the care home, did the district nurses listen and discuss things fully with the patient or you?	y=4, n=1, na=321
	During the final three months, did patient have a key contact person to rely on to get things done?	y=234, n=70, m=22
	Was patient aware of going to die because of illness?	y=278, n=25, m=23
	Was it likely that any health professional discussed with the patient regarding the likelihood of dying of the illness?	y=163, n=62, na=48, m=53
	Over the last week, was full information given to patient and family?	y=223, n=100, m=3
	Did the patient discuss their preferred place of death with any health professional?	y=147, n=104, m=75
Variable domain	**Question variable**	**Categories (y=yes, n=no, na=not-applicable, m=missing)**
Quality of nonmedical care provided at home (=6)	Did the patient have any help from a paid home care worker in the patient's final three months?	y=76, n=247, m=3
	Did more than two family or friends look after or help take care of the patient in the patient's final three months?	y=152, n=162, m=12
	Did family & friends help the patient for more than 9 hours per week with personal care in the patients final three months?	y=174, n=141, m=11
	Did family & friends help the patient for more than 9 hours per week with household tasks in the patient's final three months?	y=189, n=119, m=18
	Was patient managing financially well in the last three months?	y=298, n=26, m=2
	Did health and social services take care of the patients personal needs at home during the last 3 months?	y=159, n=95, na=70, m=2

Quality of medical care provided at home (=7)	Did the patient get as much help as needed from the GP at home?	y=205, n=88, na=31, m=2
	Was overall rating of care from the GP at home good to excellent?	y=227, n=67, na=31, m=1
	Did the patient get as much help at home as needed from the team from hospice, palliative care, Marie Curie or Macmillan or other specialists?	y=170, n=85, na=64, m=7
	Was overall rating of care from teams from hospice/palliative care visit at home good to excellent?	y=192, n=64, na=64, m=6
	Did the patient get as much help as needed from the nurses?	y=214, n=52, na=53, m=7
	Was overall rating of care from the district/community nurses at home good to excellent?	y=221, n=41, na=53, m=11
	Was overall rating of care from all the services at home good to excellent?	y=210, n=55, na=56, m=5
Quality of medical care provided outside the home (=8)	Did hospital staff take care of the patients personal needs as well as they should have?	y=174, n=46, na=105, m=1
	Did the patient get as much help and support as needed from the hospital doctors?	y=179, n=71, na=74, m=2
	Was overall rating of care from the hospital doctors good to excellent?	y=193, n=56, na=73, m=4
	Did the patient get as much help and support as needed from the hospital nurses?	y=157, n=89, na=77, m=3
	Was overall rating of care from the hospital nurses good to excellent?	y=193, n=54, na=73, m=6
	Was it very helpful was it to see the palliative care or Macmillan team at the hospital?	y=122, n=58, na=145, m=1
	Was overall rating of care from the palliative care or Macmillan team good to excellent?	y=110, n=69, na=145, m=2
	Did patient get as much help and support as needed from all the services at the hospital?	y=163, n=87, na=73, m=3
	Was overall rating of care while from all the services at the hospital good to excellent?	y=185, n=64, na=73, m=4
	Did patient get as much help and support as needed from all the services at the hospice?	y=41, n=4, na=281
	Was overall rating of care from all the services at the hospice good to excellent?	y=43, n=2, na=281
	Did patient get as much help and support as needed from all the services at the nursing/residential home?	y=17, n=7, na=301, m=1
	Was overall rating of care from all the services at the nursing/residential home good to excellent?	y=20, n=4, na=301, m=1
Variable domain	**Question variable**	**Categories (y=yes, n=no, na=not-applicable, m=missing)**
Carer factors (=9)	Number of days respondent was off work before patient died	Less than 16=62, More than 16=105, na=145, m=14
	Relationship of respondent with patient	Spouse/partner=91, Son/daughter=176, Other [relative, friend, neighbour]=59
	Was respondent aware the patient was going to die because of illness	y=282, n=37, m=7
	Did the patient discuss his/her preference with the respondent, family members or friends?	y=228, n=90, m=8
	Was home the place where the respondent would have preferred the patient to die 3 months before death	y=266, n=41, na=18, m=1